

# Cystic Fibrosis Center Newsletter

## Welcome to new Peds Provider

Dr. Barbara Stewart has joined our CF Center. She has many years of experience in CF, including research, working at several CF centers in various states as well as co-director and Director of a CF center.

She has worked at the University of Iowa Hospitals and Clinics where her research interests centered mainly on nebulizer therapies, including particle size airway deposition and medications such as Tobramycin, Pulmozyme, and the like. "I had the privilege of working with some of the greatest researchers in C.F."

"We also conducted studies on the effects of a new invention not yet on the market: the vest. The original prototype was so cumbersome and unwieldy that it wasn't practical. We showed that this concept would work for airway clearance, and further study in design, materials, etc. would result in a revolutionary tool for airway clearance."

In her free time Dr. Stewart enjoys photography and baking. "When I lived in Arizona my photography was used in commercially available greeting and note cards. I was able to capture the highly unique and unusual. Later I was invited to display many of these pieces at an art exhibit sponsored by the State University there."

Another hobby is baking and creating. "I am the person who doesn't bother with measuring cups, measuring spoons and the like."

## Masks

As we return back to "normal" the CF Foundation recommends that all people with CF wear a mask when in a healthcare facility to reduce the risk of

transmission or acquisition of CF pathogens. Masks should be worn throughout the facility, including in the restrooms. Masks do not have to be worn during pulmonary function testing, in the clinic exam room, or in the patient's hospital room. If the optimal size mask is not available (ie: for small infants), use the smallest mask available. If a mask is not tolerated by an individual with CF who is having respiratory distress, encourage that person to follow Respiratory Hygiene practices. Masks should be changed if damp or wet.

Source of supporting evidence: 2007 transmission guideline,  
Category 1B

As an accredited CF Center we follow the CF Foundations guidelines.

## Return to Clinic Project results

The results are in! Many of you worked hard to meet the CF Foundation Care Guidelines for visits and lab tests. Congratulations to those who completed the requirements and received a gift card.

## Research Update

OSF Saint Francis Medical Center recently participated in the Simplify study. Some of you were participants. The results of this study were shared with the study staff at the recent North American Cystic Fibrosis Conference. The Simplify study looked at people with cystic fibrosis ages 12 and older, who are also on Trikafta® to see if they experienced a change in lung function when they stopped either hypertonic saline OR dornase alfa (Pulmozyme®). Participation included a screening

visit, three additional onsite visits, and one visit over the telephone. Participation was over six weeks. The study found that participants who were relatively healthy were able to safely stop taking ONE of the medications without negative effects, while also taking Trikafta®. Those who participated did not show a reduction in lung function, nor did they experience an increase in respiratory symptoms during their study participation. Additional studies are needed to understand further impact of decreasing or removing therapies. It is important to discuss changes in your medication with your CF doctor before removing a medication or therapy. At this time, CFF has not yet made any formal recommendations about removing or decreasing either of these medications in people with CF.

There are more ongoing studies looking at the long-term effects on the health of CF patients while decreasing treatment burden, including HERO-2 and CF-STORM.

HERO-2 is collecting patient reported data about the use of Trikafta® and other CF treatments.

CF-STORM is similar to Simplify but is looking at the withdrawal of hypertonic saline OR dornase alfa (Pulmozyme®) over a 12-month period.

The findings of the Simplify study were published in November 2022 in the scientific journal The Lancet Respiratory. The link to that article is below. If you want to learn more about this pivotal trial or other ongoing trials, speak with you or your child's CF doctor or research nurse.

#### Sources:

CFF Website: <https://www.cff.org/news/2022-11/simplify-study-indicates-potential-reduce-medication-burden-people-cf-taking-trikafta>

Lancet article:

[https://www.thelancet.com/journals/lanres/article/PIIS2213-2600\(22\)00434-9/fulltext](https://www.thelancet.com/journals/lanres/article/PIIS2213-2600(22)00434-9/fulltext)

## Medicaid and SNAP

The increase in SNAP benefits during the COVID-19 pandemic will end in March. For households that receive SNAP and Social Security benefits, SNAP benefits will decrease because of the recent cost of living increase to Social Security benefits.

If you have Medicaid insurance, make they have your updated mailing address so you do not lose coverage.

**Medicaid coverage:** Starting on April 1, states will be allowed to terminate Medicaid coverage for people who are no longer eligible; states must inform beneficiaries that they will lose coverage.

Is your address up-to-date so that you receive renewal paperwork or information about your coverage ending? To ensure your address is correct and/or to make changes, go to:

- Go to [abe.illinois.gov](http://abe.illinois.gov), click "Manage My Case", and log in or create an account
- Call the ABE hotline at 1-800-843-6154
- Call the HFS hotline at 877-805-5312
- Go to [ww2.illinois.gov/hfs/address](http://ww2.illinois.gov/hfs/address)

A health insurance marketplace special enrollment period for qualified individuals and their families who lose Medicaid or CHIP coverage will be open from Mar. 31 to Jul. 31. on [healthcare.gov](http://healthcare.gov).

If you are going to lose access to Medicaid, contact your CF team or contact CF Compass at 1-844-266-7277 so a case manager can help you review and compare other health insurance and financial assistance options.

## Reminders

Warm weather is coming and we will all be outside more in the coming months. Things to keep in mind as we head outside

\*\* Don't forget to hydrate. Beverages with sodium and electrolytes (sports drinks, hydration packets, etc.) are essential if you are physically active.

\*\*check out your local Park district for activities to help your kids be active over the summer.

**Free exercise program:** The CF Foundation is extending its support for free access to Beam, an online exercise, education, and well-being platform. People with CF ages 18 and older can enjoy a variety of on-demand and live free classes through June 2023. Visit [beamfeelgood.com](http://beamfeelgood.com) for more information.

## Important Info about Appointment Reminders

If you get a MyChart/EPIC reminder about your CF clinic appointment, please be aware that the phone number listed in the reminder message is incorrect. The number given is for the Peds Pulmonary Department. Do not call this number. If you need to cancel or reschedule a clinic visit, call 309-624-6565.

### Change to clinic appointment reminders

In an effort to communicate but not frustrate you we are changing our process for CF clinic appointment reminders. You will receive 2 communications from the CF clinic about your upcoming appointment:

- 1) Letter mailed to you 1 month prior
- 2) MyChart message or phone call 2 days prior

## Calling clinic with illness symptoms

If you are calling clinic with illness symptoms or if you suspect you have a pulmonary exacerbation, it is helpful if you have recent PFT results from your home spirometry. If you haven't used your home spirometry recently, please complete a test before calling clinic.

## Spring Recipe

### Pea Salad

#### Ingredients

- 4 cups frozen peas (about 16 ounces), thawed
- 1 cup chopped celery
- 2 hard-boiled large eggs, chopped
- 1/4 cup chopped green onions
- 1 cup cubed cheddar cheese
- 1/2 cup thinly sliced radishes or 1 jar (2 ounces) pimientos, drained
- 1 cup mayonnaise
- 3 tablespoons sweet pickle relish
- 1 teaspoon sugar
- 1 teaspoon seasoned salt
- 1 teaspoon ground mustard

#### Directions

In a large bowl, combine the first 6 ingredients. In a small bowl, combine mayonnaise, relish and seasonings. Stir into pea mixture. Cover and refrigerate until serving.

#### Nutrition Facts

3/4 cup: 325 calories, 27g fat (7g saturated fat), 65mg cholesterol, 574mg sodium, 12g carbohydrate (6g sugars, 3g fiber), 9g protein.

#### Source

<https://www.tasteofhome.com/recipes/pea-n-cheese-salad/>

